

treatment with demonstrated impact on QOL only on a delayed basis. BMT centers are more likely to be a source of referral than eye care providers. There is now increased availability of autologous serum, scleral lenses, and PROSE treatment. Increasing awareness among these BMT clinicians, eye care providers, and patients presents an opportunity for impact as far as improvement QOL for HSCT survivors.

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Integrating Palliative/Supportive Care Concepts in the Blood and Marrow Transplant Setting

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The availability of Blood and Marrow Transplant (BMT) can provide hope and possibly life for patients with certain acute and chronic diseases that have no hope for cure. Unfortunately treatments that are necessary to achieve a cure can illicit untoward symptoms that seriously impact quality of life (QOL). While the goal of treatment may be cure, the challenge of treatment becomes managing the burden of those symptoms and maintaining a QOL that makes that cure worth the journey.

Symptom burden in the transplant setting presents a challenge to both the patient and the medical team. High dose chemotherapies with high emetogenic potential can illicit severe nausea and vomiting both acute and delayed. Some acute complications of transplant include mucositis, anorexia, pain, graft versus host disease and immunosuppression. Acute symptoms can become chronic. To address symptom burden it seems logical that the experts in each of these disciplines, BMT and palliative/ supportive medicine, should partner to give these patients the best possible outcome.

Obstacles to excellent palliative/supportive care in the BMT setting can occur when consults are based on clinician values, rather than patient needs. Many clinicians mistakenly believe palliative/supportive care translates to end of life care. The World Health Organization reports palliative/supportive care is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

The intent of this paper is to outline a proposal for the integration of palliative/supportive care concepts in the BMT setting that can facilitate the transformation of the latest knowledge into strategies that help to manage the burden of symptoms in the BMT setting.

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Body Mass Index as an Indicator of Prognosis in Patients Undergoing Allogeneic Hematopoietic Stem Cell Transplantation: A Single Institution Experience

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Both obesity and malnutrition are considered risk factors for complications and increased relapse and nonrelapse mortality in hematopoietic stem cell transplantation (HSCT). An inferior outcome after allogeneic HSCT has been reported in obese adult patients in both allogeneic and autologous HSCT: Overweight individuals seem to develop more complications of graft versus host disease and more

infections than its normal counterparts. Between March 1996 and December 2010, a total of 138 patients received an allogeneic HSCT in the Centro de Hematología y Medicina Interna of the Clinica Ruiz. Patients were stratified according to pretransplantation body mass index (BMI) values: 17 patients had low BMI, 62 had normal BMI and 59 patients had high BMI. Median overall survival (OS) for these three groups were respectively 9, 12 and 22 months. Patients with a low BMI had a lower OS than those with a normal BMI (58-month OS of 24% versus 32%), whereas patients with an increased BMI had a better outcome (median OS of 22 months and 43% OS at 130 months) than those with a normal BMI. Our findings demonstrate a correlation between pretransplantation BMI and posttransplantation survival and should provide insight into how to better manage nutritional support for patients undergoing HSCT.

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Factors Impacting Family Decisions to Pursue Transplantation for Children with Sickle Cell Disease

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Background: The only cure currently available for sickle cell disease (SCD) is hematopoietic stem cell transplantation (HSCT). Barriers preventing widespread application of HSCT include limited donor pools and lack of family education about HSCT. To our knowledge, no studies have examined medical and psychosocial factors that influence families' decisions about whether or not to pursue HSCT for their child with SCD.

Methods: Surveys created by members of the Sickle Cell, Blood and Marrow Transplantation, and Psychosocial teams were distributed to family members attending an education symposium about HSCT for SCD at a large metropolitan hospital. Surveys were anonymous, optional, and approved by the Institutional Review Board; participants were entered into a gift card drawing. On a scale from 0 ("not important at all") to 3 ("very important"), participants rated the relative importance of 17 factors that may impact the decision to pursue HSCT.

Results: Thirty-four attendees completed surveys; 15% were parents/guardians of patients who had already had a transplant (n = 5), 73% were parents/guardians of patients who had not had a transplant (n = 25), and 12% were "other" family members (n = 4; e.g., aunt, grandmother). Items that were consistently rated important (i.e., >80% of respondents rated them "somewhat important," "important," or "very important") represented multiple domains, including: HSCT-related risks (e.g., death, infertility, transplant failure, GVHD), prevention of SCD complications, medical team interactions (e.g., hematologist recommendation, trust in medical team), and psychosocial concerns (e.g., emotional strain on patient/parents, social support). Items not consistently rated important included financial strain, impact on sibling donor, child losing hair, child missing school, and religious beliefs. Mean importance ratings were highest for risk of death (M = 2.91) and prevention of SCD complications (M = 2.82) and lowest for religious beliefs (M = .68) and child losing hair (M = 1.00). See for importance ratings of individual survey items. There were few differences between ratings of family members who had been through transplant and those who had not.

Conclusions: When considering HSCT for SCD, parents and caregivers report HSCT-related risks, interactions with

medical teams, and emotional effects as most important to their decision. Results emphasize the importance of ongoing education for families, the role of the family-physician relationship, and the value of psychosocial support throughout the transplant process. Although the current study is limited by a small convenience sample that may not be representative of the large sickle cell population (i.e., self-selection to attend the symposium may indicate greater interest in pursuing transplant), these findings provide important insight into the complexity of family decisions about HSCT.

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Late Pneumocystis Pneumonia After HSCT: Atypical Presentation and Lack of Correlation with CD4 Count

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Duration of *Pneumocystis pneumonia* (PCP) prophylaxis after allogeneic HSCT is not well defined. Guidelines recommend at least six months, and longer for patients on immunosuppression. We report six cases of PCP that happened late after allo-HSCT (median 36 months, range 19–80). All had received peripheral blood HSCT: three from matched sibling donors (MRD), and three from matched unrelated donors (MUD) (the latter with alemtuzumab conditioning). At the time of PCP, three patients (#3, #4, #5) were not on immunosuppression and had no active graft versus host disease (GVHD). Their mean CD4 T cell count was 569 (range 411–664). The other three had late-acute (#6, post-DLI) or chronic (#1 and #2) GVHD. Only #1 was on prednisone (< 0.5 mg/kg); #2 and #6 were on MMF alone. Their mean CD4 T cell count was 210 (range 86–380). #1 and #5 were on PCP prophylaxis (dapsone, atovaquone).

Clinical presentation was atypical. Subacute fever without shortness of breath (SOB) was most common. Patient #1 was asymptomatic, with diffuse infiltrates found on restaging chest CT. Only #2 presented with acute SOB and hypoxemia.

All patients had ground-glass opacities, but these were patchy/multifocal (n=4) rather than diffuse (n=2). PCR was more sensitive than DFA or GMS. Response to TMP/SMX ($\bar{A} \pm$ steroids) was uniformly positive.

Conclusion: PCP may occur late after transplant, even in the absence of immunosuppressive therapy, active GVHD or CD4-T lymphopenia. Patchy ground-glass opacities and nonspecific infiltrates are the common radiologic feature. Post-transplant CD4 count does not seem to be useful to predict PCP or the need for prophylaxis. It is possible that a qualitative immune T cell defect accounts for late PCP.

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Palliative Care Intergration into an Acute Leukemia and Bone Marrow Transplant Program

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Advancements in bone marrow transplant (BMT) have led to an increasing number of patients surviving both their initial cancer diagnosis, and the aggressive treatment used to cure the cancer. However for most patients, this cure comes at a significant cost. Complications from BMT and chemotherapy regimens lead to chronic conditions, which impact both quality and quantity of life. Palliative care is not only for dying patients; It provides support for symptom management, emotional support, and advance care planning for any patient and family member facing serious illness. Most importantly, palliative care improves communication between the primary physician and family members, and assists with sometimes very difficult life questions. Clinical integration of two palliative care MD clinic sessions have been embedded into the BMT clinic workflow in February 2012. The purpose is to measure outcome support for the staff, patient and family members on an outpatient basis and increase palliative care physician referrals from the Bone Marrow Transplant program. In addition, a goal is to increase patient/family and team planning for end of life care and to decrease the number of hospital deaths among Bone marrow

Tabel 1

Patient #	1	2	3	4	5	6
Age, gender	46M	35M	51M	46M	55M	54M
Disease	DLBCL	HD	DLBCL	MZL	TCL	CLL
Months after Tx at PCP	36	58	36	19	80	27
HSCT donor	MUD (campath)	MRD	MUD (campath)	MUD (campath)	MRD	MRD
aGVHD	GI	No	GI, skin	No	Skin	Skin, liver post-DLI
cGVHD	Mouth, upper GI, eyes	Extensive	No	No	No	No
GVHD Rx	Prednisone, topical steroids	MMF, azithromycin, montelukast	None	None	None	MMF, topicals
CD4 (334-1556)	86	380	411	631	664	164
PCP prophylaxis	Dapsone	No	No	No	Atovaquone	No
Presentation	Asymptomatic	Acute SOB cough	Subacute fever	Subacute fever	Subacute fever; cough	Subacute fever; cough
CT	Diffuse reticular and ground glass opacity	Ground glass opacities, focal consolidation in both upper lobes, and RML	Diffuse multifocal ground glass and reticular opacities in both lungs.	Bilateral ground glass infiltrates.	Multi focal nodular and diffuse infiltrates.	RLL consolidation and patchy ground glass opacities in RML and LLL.
BAL	GMS+	GMS+	GMS+	GMS-	GMS-	GMS-
	DFA+	DFA+	DFA+	DFA-	DFA-	DFA+
	PCR+	PCR+	PCR+	PCR+	PCR+	PCR+